



MEDIA RELEASE

5 September 2017

**Stay in Bed or Light Up for Mito during
Global Mitochondrial Disease Awareness Week, 17-23 September 2017**

At least 30 Australian children (1 in 200) born every week are at risk of developing some form of mitochondrial disease, a disabling and potentially fatal disorder that's now the second most commonly diagnosed serious genetic disease after cystic fibrosis.

Globally, it's estimated 37.5 million children and adults may suffer with mitochondrial disease or could pass it to their unborn children, yet few people had heard of 'mito' until UK baby Charlie Gard's recent tragic plight sparked worldwide sympathy and calls for more research.

That's why the Australian Mitochondrial Disease Foundation (AMDF) is urging the public and the medical community to find out more about 'mito', increase awareness and help raise funds for research, patient support and education during **Global Mitochondrial Disease Awareness Week** from 17-23 September.

Highlights include **Light Up for Mito** on 16 September, when more than 55 landmarks around the world will be illuminated in green in a 24-hour world record attempt, and **National Stay in Bed Day** on 24 September, when Australians can earn a guilt-free sleep-in or pyjama day simply by donating to find a cure for mitochondrial disease.

AMDF CEO Sean Murray said mitochondrial disease is a complex disorder that robs the body's cells of energy, starving muscles and major organs of the power they need to function properly.

"There are few treatments and no cure for mito, which can cause any symptom in any organ at any age. However, 90 per cent of affected people are misdiagnosed, undiagnosed or may unknowingly pass mitochondrial disease on to their unborn children," Mr Murray said.

"We encourage everyone to stay in bed, 'light up for mito', share information on social media and make a donation during Global Mitochondrial Disease Awareness Week to help the AMDF raise awareness and much-needed funds for vital research into a cure."

Global Mitochondrial Disease Awareness Week features fundraising activities, advocacy and social media initiatives and information sessions. Highlights include:

- In **Light Up for Mito**, more than 55 monuments in Australia and around the world will glow green on 16 September in a world record attempt for the most landmarks illuminated in 24 hours, from Canada's Niagara Falls and Rome's Colosseum to Adelaide Oval, the Melbourne Star and Canberra's Old Parliament House (gmdaw.org).

People can also Light Up for Mito by installing a green light bulb outside their home or business for the week and sharing a photo on social media using #lightupformito.

- On **National Stay in Bed Day** – a 'Sleep-in to Cure Mito' – Australians can lie-in guilt-free on Sunday 24 September by donating at stayinbedday.org.au or holding pyjama parties at their workplace or school during September.
- The **AMDF Symposium** in Melbourne on 21 September brings together Australian and international experts to discuss the latest on mitochondrial donation, an innovative IVF therapy to enable affected women to have healthy babies free of the disease (amdf.org.au).
- **The Bloody Long Walk** in Perth on 17 September and Sydney's East on 24 September, two of seven 35km fundraising 'walks to cure mito' from August to November (bloodylongwalk.com.au).

More about mitochondrial disease

AMDF CEO Sean Murray said mitochondria are the powerhouses within our cells that transform food and oxygen to generate 90 per cent of the energy fuelling our bodies, particularly muscles and major organs like our brain, heart, liver, ears and eyes.

“Lifestyle and environmental factors damage our mitochondria and make them less effective over time, so mitochondrial *dysfunction* is a significant factor in a range of major diseases and is a key reason humans develop age-related health problems and have a finite lifespan.

“People with mitochondrial *disease* have genetic mutations that predispose their mitochondria to fail prematurely, which means they may develop mitochondrial disease symptoms anytime in their lives. Awareness of mito in the medical community remains relatively low, particularly for adult-onset and non-life-threatening forms of the disease.

“Mitochondrial disease can affect both children and adults; due to its genetic basis, the disease often affects multiple family members. Mito can be inherited from a person’s mother, father or both parents, or can arise as a spontaneous genetic mistake at conception.

“Depending on which parts of their bodies are affected and to what degree, sufferers may: lose their sight or hearing; suffer muscle weakness and pain; be unable to walk, eat, swallow or talk normally; have strokes or seizures; develop liver disease or diabetes; or suffer heart, respiratory or digestive problems, developmental delays or intellectual disability.

“The AMDF hopes Australian women will one day be able to access a ground-breaking new IVF technique to avoid passing maternally inherited mitochondrial disease to their baby. Called mitochondrial donation, the technique transplants a small number of healthy cells from a donor egg to replace the mother’s faulty mitochondrial DNA.

“Mitochondrial donation has been approved in the United Kingdom, but Australian laws need to change to give affected women the choice to access the technique here.”

About the Australian Mitochondrial Disease Foundation

The AMDF does not receive government funding and relies solely on donations.

Since it was set up in 2009 by family members, friends and doctors of sufferers, the AMDF has funded major research projects, an Australia-wide mitochondrial patient database and priority access to a new Next-Generation DNA Sequencing Facility to enable faster, less expensive and more accurate diagnoses of mitochondrial disease.

The AMDF raises funds through National Stay in Bed Day (stayinbedday.org.au) and The Bloody Long Walk national series of 35km walks in capital cities from August to November (bloodylongwalk.com.au). Other community initiatives are held during the year by the AMDF, groups, families and individuals.

The AMDF operates a telephone helpline (1300 977 180), runs support groups including teleconferences and a Facebook group, and holds information days and symposia for patients, GPs, specialists and the public.

For media information and interviews with the AMDF, experts and people affected by mitochondrial disease, please contact:

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The **AMDF Media Resources Dropbox** at <http://tinyurl.com/n9w963c> contains media releases, fact sheets, images, audio and community service scripts, plus information on the likely number of people with mito in your area.

Visit amdf.org.au for further information and personal mito stories.